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published in
European Journal of Gastroenterology and Hepatology
2009

DOI (link to publisher)
10.1097/MEG.0b013e328315a215

document version
Publisher's PDF, also known as Version of record

Evaluation of a psychoeducational intervention for adolescents with inflammatory bowel disease

Martha A. Grootenhuis[a], Heleen Maurice-Stam[a], Bert H. Derkx[b] and Bob F. Last[a,c]

Objectives **Inflammatory bowel disease (IBD), comprising Crohn's disease, ulcerative colitis, and indeterminate colitis, often has its onset in adolescence. The aim of this study was to evaluate whether a psychoeducational group intervention (aiming to enhance information seeking and giving about the disease, relaxation, social competence, and positive thinking) can strengthen the coping efforts of adolescents with IBD and have a positive effect on their Health-Related Quality of Life (HRQoL).**

Methods **Adolescent IBD patients from the Emma Children's Hospital AMC and adolescent members of the Crohn and Ulcerative Colitis Association in The Netherlands, were invited to participate in The intervention study. Using reliable and valid self-report instruments the adolescent's coping styles, feelings of competence, and HRQoL were assessed before and 6–8 months after the intervention. The parents were asked to fill in the Child Behavior Check List. Linear regression analyses were performed to test whether group participation was predictive of the outcome measures while correcting for the first measurement occasion and sex.**

Results and conclusion **Forty patients responded positively to invitation to the intervention. Eighteen adolescents, however, lived too far away to attend and served as a control group. Twenty-two children were enrolled and attended in groups of four to six children in six group sessions, supervised by two psychologists. The intervention seemed to have a positive effect on: coping (predictive control, $P<0.01$), feelings of competence (global self-worth, $P<0.05$ and physical appearance, $P<0.01$), and HRQoL (body image, $P<0.05$). These results give good reason to continue this intervention study with a larger population.** ***Eur J Gastroenterol Hepatol*** **21:340–345 © 2009 Wolters Kluwer Health | Lippincott Williams & Wilkins.**

European Journal of Gastroenterology & Hepatology 2009, **21**:340–345

Keywords: adolescence, anxiety, Health-Related Quality of Life, inflammatory bowel disease, self-esteem

[a]Pediatric Psychosocial Department, [b]Department of Pediatrics, Emma Children's Hospital, Academic Medical Centre, University of Amsterdam and [c]Department of Developmental Psychology, Faculty of Psychology and Education of the Vrije Universiteit Amsterdam, The Netherlands

Correspondence to Martha Grootenhuis, Pediatric Psychosocial Department, Emma Children's Hospital, AMC, G8-224, Meibergdreef 9, Amsterdam 1105 AZ, The Netherlands
Tel: +31 20 5665674; fax: +31 20 6091242;
e-mail: m.a.grootenhuis@amc.uva.nl

Received 6 April 2008 **Accepted** 19 August 2008

Introduction

During the last years it has become increasingly acknowledged, also scientifically, that inflammatory bowel disease (IBD) in adolescents has many psychosocial consequences [1–3]. Considering the frequent onset in adolescence and the symptoms the children experience, they are at risk for social problems and limited social activities [4], psychosocial adjustment problems [5] or depression [6]. Recently, we described Health-Related Quality of Life (HRQoL) and psychosocial functioning of 40 adolescents who were interested in participating in a psychosocial intervention. The adolescents, especially boys, reported significantly worse HRQoL, and more internalizing problems than healthy peers [1]. In addition, we have demonstrated the importance of coping, particularly positive thinking, and self-perception as predictors of HRQoL in adolescents with IBD [1,7]. Both are important determinants, for which patients could receive training during a psychosocial intervention.

Psychosocial group interventions are becoming increasingly important in the treatment of children with chronic diseases. These group interventions allow them to treat more children simultaneously, and gives them the opportunity to benefit from sharing emotions and experiences. Results from the studies of psychological interventions for children and adolescents with chronic medical conditions provide strong evidence that interventions are effective [8]. Group interventions have been used within a variety of pediatric populations. The focus has been on emotional support (e.g. living with cancer), enhancing disease-specific skills (e.g. coping with diabetes, asthma), and reduction of physical symptoms by behavior change (e.g. encopresis, obesitas). Studies on the effectiveness of group interventions show promising

0954-691X © 2009 Wolters Kluwer Health | Lippincott Williams & Wilkins DOI: 10.1097/MEG.0b013e328315a215

results, in particular in establishing coping skills and improving knowledge about symptom reduction and disease-related problem solving [8].

Recent results of intervention studies have been reported for children or adolescents with IBD only. Szigethy *et al.* [9] studied the effectiveness of cognitive-behavioral therapy for depression in adolescents with IBD. It seemed to be a promising intervention.

The purpose of this study was to investigate the effectiveness of a psychoeducational group intervention for adolescents with IBD. The program was designed with the aim to empower adolescent IBD patients by teaching the active use of coping strategies. Coping strategies focused on seeking information about the disease, using relaxation techniques, proactive behavior with peers, and positive thinking to increase self-worth and social-emotional functioning. We hypothesized that IBD patients who participated in the intervention scored more favorable thereafter than a control group of IBD patients who did not participate. We expected more positive thinking, higher self-worth, better HRQoL, and less anxiety and behavioral-emotional problems among the participants in the intervention than in the control group.

Materials and methods

Intervention

The psychoeductional group intervention for adolescents with IBD is part of the intervention program Op Koers (OK program) developed for different age groups by the Pediatric Psychosocial Department the Emma Children's Hospital AMC [10]. For adolescents with IBD some disease-specific aspects were added to the intervention.

The OK program is based on Beck 's cognitive theory [11,12] and the cognitive behavior therapeutic approach that integrates behavioral procedures such as modeling, contingency management, exposure exercises, and cognitive techniques [13]. The techniques used in the OK program proved to be effective in behavioral and cognitive-behavioral therapeutic programs in children with somatic complaints [14,15] and in children with behavior and/or anxiety disorders [16,17]. Exemplary element of the intervention in classic behavioral therapy is learning an alternative, concurrent response (e.g. active muscle relaxation) in facing a stressful, anxiety-evoking procedure (e.g. a venapuncture). This procedure was found to be effective in several studies in hospitalized children [14].

Main goals of the OK program are as follows. Information seeking and information giving about the disease is trained in the intervention by asking the adolescents to tell the story of their disease. They are all encouraged to seek information and ask information because it is 'good to know better'. Information sources are discussed. Adolescents are taught in role playing about approaching the physician with questions about the disease and treatment. 'Relaxation' is practiced through different exercises. The enhancement of 'social competence' is taught by story telling and group discussions about the activities that adolescents can or cannot do because of the disease. Feelings of being different because of the illness are discussed. 'Positive thinking' is encouraged by identifying and correcting inaccurate thoughts and discourage negative self-talk. For a comprehensive description of the intervention we refer to Table 1 and Last *et al.* [10].

Table 1 Description of the sessions

Session		
1	Content session	Introducing the intervention Getting to know each other Thermometer TFD model + SoF Questions others ask you about your disease
	Homework	Read about TFD model
Start of every session		Questionnaires Thermometer Nice and new: last week Discussion homework
2	Content session	It is good to know better Discussion about sources of information Relaxation practice
	Homework	Formulate questions Relaxation exercice (CD)
3	Content session	Open communication Role play approaching physician Video: take initiative and inform
	Homework	Tell the story of your disease
4	Content session	Discussion being different My personal competencies game
	Homework	Make a list of everything you can do
5	Content session	Recognizing negative thinking Identifying and correcting inaccurate thoughts Relaxation
	Homework	Describe three negative thoughts Identify and correct them
6	Content session	Giving compliments Repetition goals of the program Evaluation

SoF, spin-of feelings; TFD, thinking-feeling-doing.

Procedure

Inclusion criteria for the study are: aged between 12 and 18 years, sufficient command of the Dutch language and diagnosed with Crohn's disease, ulcerative colitis or indeterminate colitis (IBD) for at least 6 months. A total of 235 adolescents with IBD were invited by letter to participate in the intervention study; 87 adolescents who were under medical care at the Emma Children's Hospital AMC and 148 members of the Crohn and Ulcerative Colitis Association in the Netherlands, USA. Of those, 40 patients were interested in participating in the intervention and 74 patients replied that they did not wish to participate. The other 121 patients did not respond [1].

All 40 adolescents who were interested in joining the intervention and participating in the study completed the questionnaires at baseline. The 18 adolescents who lived too far away to participate in the intervention at the Emma Children's Hospital AMC were placed on a waiting list (control group). The remaining 22 participated in the intervention (experimental group). The 18 adolescents on the waiting list were administered questionnaires at intervals simultaneously with the experimental group.

Participants of the study were asked to complete questionnaires three times: before the intervention (baseline), 0–6 weeks after the intervention, and 6–8 months after the intervention. To investigate the effects of the intervention, data at baseline were compared with data of 6–8 months after the intervention, as we were mainly interested in the long-term effects of the intervention.

The Medical Ethic Committee of the Academic Medical Center in Amsterdam has approved the study protocol.

Measures

Patient report

The Cognitive Control Strategies Scale for pediatric patients, developed at the Psychosocial Department of the Emma Children's Hospital AMC [18–20], was used to measure disease-related cognitive coping. Higher scores represent a stronger reliance upon the control strategy. The items of the Cognitive Control Strategies Scale were grouped into three scales: predictive control (three items, being optimistic about the course of the illness), vicarious control (eight items, attributing power to medical care givers and treatment), and interpretative control (four items, searching for information to better understand emotional reactions and to gain insight into the situation). The internal consistency of the scales was satisfactory, ranging from 0.74 to 0.98.

The Self-Perception Profile for Adolescents was used to assess patients' self-worth [21]. Several aspects of self-perception were measured: school competence, social acceptance, athletic competence, physical appearance, behavioral conduct, global self-worth, and close friends. The Cronbach's α of the Self-Perception Profile for Adolescents scales were satisfactory, ranging from 0.70 to 0.90.

Anxiety was measured with the Dutch version of the State-Trait Inventory for Children, the ZBV-K [22]. The 'trait' version was used to assess the tendency to respond with anxiety in a threatening situation. This version is more appropriate to measure the overall level of anxiety of a child's experiences than the 'state' version that measures conditional anxiety at the very moment of assessment. Higher scores indicate higher levels of anxiety. The validity and reliability turned out to be good [22]. The Cronbach's α in this study were satisfactory, ranging from 0.90 to 0.94.

The evaluation of the quality of daily functioning was measured with the Dutch Children's AZL/TNO Quality of Life Questionnaire (DUX-25) [23]. The DUX-25 assesses the affective appraisal of daily functioning in children and consists of a total score and four domains: family functioning, body image, emotional functioning, and social functioning. The items reflect children's feelings about themselves, their parents, and friends, and feelings about daily routines at home and at school. Higher scores represent better HRQoL. Although no validation studies have been published yet, the DUX-25 is reported to be internally consistent and reproducible [23,24]. The Cronbach's α in this study were satisfactory, ranging from 0.78 to 0.94, with the exception of the Social scale ($\alpha = 0.59$). This scale was not used in analyses.

Parent report

The Dutch Child Behavior Check List (CBCL) for parents was used to assess patients' behavioral-emotional problems as reported by the parents [25]. The following scales were used in this study: internalizing problems, externalizing problems, and the total score. The Cronbach's α of the scales were satisfactory, ranging from 0.87 to 0.95. Questions about the patient's demographic and medical characteristics were administered to the parents.

Statistical analyses

The Statistical Package for Social Sciences, Windows version 11.5, was used for all analyses. To detect attrition bias, 6–8 months after the intervention, respondents and nonrespondents were compared with respect to their demographic and medical characteristics, and their outcomes scores at baseline. The same tests were performed to compare the intervention group with the control group to detect confounding variables.

The effect of the psychoeducational group intervention was investigated in two ways. First, to get an indication of the intervention effect, outcome scores 6–8 months after the intervention were compared with baseline outcome scores. Nonparametric Wilcoxon-signed ranks were conducted for the intervention group and the control group separately, using an explorative significance level of P value of less than 0.05. Second, linear regression analyses were performed to test the effect of the intervention. Patient's scores on the outcomes 6–8 months after the intervention were predicted by the condition (intervention or not), adjusted for sex and the baseline score on the outcome variable in question. To compensate for multiple testing, we considered an intervention effect to be established only if the standardized regression coefficient (β) was higher than 0.25 in combination with a significance level of P value of less than 0.05.

Following Cohen [26] standardized regression coefficients β of 0.1 are considered as small, 0.3 as medium and 0.5 as large. For binary coded predictor variables, β of 0.2 can be considered small, 0.5 medium and 0.8 large.

Results

Patients

Forty patients with IBD participated in the intervention study [1]. Of these, 18 adolescents were placed on a waiting list and served as control group; 12 females (66.7%) and six males (33.3%), mean age 15.4 years. The other 22 IBD patients participated in the intervention. Among them nine were females (40.9%) and 13 males (59.1%), mean age 15.7 years. Most patients suffered from Crohn's disease (Table 2).

All patients from both the intervention group and the control group completed the questionnaires at baseline. No demographic or medical differences (at $P < 0.05$) were found between the groups at baseline. We also did not find differences (at $P < 0.05$) between the two groups on the outcome variables at baseline.

All control patients completed the questionnaires 6–8 months postintervention. Eight patients (36.4%) in the intervention group did not return the questionnaires 6–8 months postintervention. The nonrespondents did not differ from the respondents 6–8 months after the intervention with respect to their demographic and medical characteristics. Some differences (at $P < 0.05$) were found on the CBCL scores at baseline: nonrespondents after the intervention seemed to suffer from less internalizing and total behavioral-emotional problems than respondents at baseline.

Outcomes

Outcome scores before and after the intervention

Six to 8 months after the intervention, the patients in the intervention group reported several improvements compared with their baseline scores, whereas in the control group no differences were found between the scores at baseline and 6–8 months after the intervention (Table 3). The intervention group reported the use of more predictive control strategies at baseline than 6–8 months postintervention. This means that they were more optimistic about the further course of the disease after the intervention than before. Furthermore, the intervention group judged their physical appearance (Self-Perception Profile for Adolescents) and body image (DUX-25) more favorable 6–8 months postintervention than at baseline. Finally, their parents reported less behavioral-emotional problems about them (total score CBCL) 6–8 months postintervention than at baseline.

Table 2 Demographic and medical characteristics of the patients from the intervention and control group, at baseline and 6–8 months postintervention

	Intervention group		Control group	
	Baseline	Postintervention	Baseline	Postintervention
N	22	14	18	18
Female sex (%)	40.9	35.7	66.7	66.7
Age (years)				
Mean	15.7	16.5	15.4	16.2
SD	1.5	1.2	1.4	1.4
Disease (%)				
Crohn	77.3	64.3	61.1	61.1
Ulcerative colitis	22.7	35.7	22.2	22.2
Indeterminate colitis	0	0	16.7	16.7
Age at diagnosis (years)				
Mean	11.1	10.2	11.7	11.7
SD	3.6	4.1	3.0	3.1

Effects of the intervention

Linear regression analyses were performed to determine whether the improvements reported in the earlier section were attributable to the intervention. Table 4 shows the standardized regression coefficients β for the effect of the intervention on the outcomes 6–8 months postintervention, adjusted for the impact of sex and the baseline score on the outcome variable in question. Considering the size of the standardized regression coefficients β, the intervention seemed to have a small-to-medium positive effect on predictive control, physical appearance, and body image. In other words, the improvements reported in the earlier section (Table 3) can be attributed to the intervention. In addition, a positive intervention effect of small effect size was found on global self-worth.

Discussion

Adolescents suffering from IBD are at risk of worse psychosocial functioning, which seemed to be associated with lower self-esteem [1]. Therefore, a psychoeducational group intervention was designed and aimed at the empowerment of adolescent IBD patients by teaching active use of coping strategies. The intervention was hypothesized to improve positive thinking (predictive coping), self-esteem and HRQoL, and to reduce anxiety and behavioral-emotional problems. Promising effects were found in the current study; the hypotheses could partly be confirmed. First, compared with baseline, the patients who participated in the intervention reported significantly more positive expectations of the further course of their disease (predictive coping) 6–8 months postintervention, whereas no improvement was found in the control group of IBD patients. Second, the intervention seemed to have a positive effect on patient's self-esteem; improvements on global self-worth and on physical appearance were found attributable to the intervention. Furthermore, consistent with these outcomes, a significant improvement in body image was also found, a domain of HRQoL. We did not find intervention effects on anxiety (State-Trait Inventory for Children) and behavioral-emotional outcomes as assessed with the CBCL.

Table 3 Mean scores of the intervention and control group, 6–8 months postintervention compared with baseline

	Intervention group ($N \approx 13$)				Control group ($N \approx 18$)			
	Baseline		Postintervention		Baseline		Postintervention	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
CCSS								
Predictive control	8.3	(1.8)	9.5*	(1.7)	8.3	(2.0)	8.1	(1.9)
Vicarious control	21.4	(4.6)	21.9	(4.1)	20.9	(3.4)	19.9	(2.9)
Interpretative control	12.8	(1.6)	12.5	(1.9)	11.4	(1.8)	11.6	(2.5)
SPPA								
School competence	14.7	(3.7)	15.4	(2.9)	14.2	(3.0)	14.5	(2.7)
Social acceptance	14.7	(3.5)	15.2	(2.5)	14.1	(3.2)	14.2	(2.8)
Athletic competence	11.8	(3.9)	12.5	(3.7)	12.2	(3.4)	11.8	(3.3)
Physical appearance	13.0	(3.9)	15.5**	(2.6)	13.4	(4.0)	13.8	(4.0)
Behavioral conduct	14.8	(3.5)	15.5	(3.5)	15.8	(1.9)	16.1	(2.1)
Close friends	16.4	(3.0)	15.8	(4.4)	16.5	(3.6)	16.4	(3.7)
Global self-worth	14.6	(3.9)	15.8	(3.6)	15.0	(3.8)	14.4	(4.0)
STAI-C	30.4	(6.8)	29.2	(8.1)	33.2	(8.1)	34.7	(9.9)
DUX-25								
Home functioning	76.9	(15.9)	79.2	(20.6)	71.5	(16.1)	76.1	(16.1)
Body image	55.4	(18.6)	68.9*	(17.7)	60.0	(17.4)	59.0	(20.1)
Emotional functioning	66.8	(16.6)	73.1	(18.4)	63.9	(11.9)	65.9	(16.0)
Total functioning	68.0	(11.4)	73.8	(15.3)	65.2	(10.6)	67.0	(13.8)
CBCL parent report								
Internalising problems	11.6	(6.3)	9.3	(7.5)	14.8	(11.8)	11.1	(9.6)
Externalizing problems	5.8	(6.1)	4.7	(6.4)	7.3	(7.1)	4.3	(3.9)
Total problems	30.6	(19.0)	23.0*	(19.5)	33.2	(27.0)	22.8	(18.8)

CBCL, Child Behavior Check List; CCSS, Cognitive Control Strategies Scale; DUX-25; Dutch Children's AZL/TNO Quality of Life Questionnaire; SPPA, Self-Perception Profile for Adolescents; STAI-C, State-Trait-Anxiety Inventory for Children.
*$P<0.05$ and **$P<0.01$ at Wilcoxon signed ranks test.

Table 4 Standardized regression coefficients β for the intervention effects, adjusted for sex and the baseline score[a]

	Predictive control (β)	Physical appearance (β)	Global self-worth (β)	Body image (β)
Intervention	0.43**	0.41**	0.27*	0.39*
Female sex	0.19	0.41**	0.12	0.21
Baseline score				
Predictive control (CCSS)	0.61***	–	–	–
Physical appearance (SPPA)	–	0.56***	–	–
Global self-worth (SPPA)	–	–	0.79***	–
Body image (DUCATQOL)	–	–	–	0.62***
R^2	0.56***	0.50***	0.64***	0.49***
DF	3.27	3.26	3.25	3.27

CCSS, Cognitive Control Strategies Scale; DF, degrees of freedom; DUCAT-QOL, Dutch Children's AZL/TNO Quality of Life Questionnaire; SPPA, Self-Perception Profile for Adolescents.
[a]Only the intervention effects that reached a significant level of P value of less than 0.05 in combination with an effect size of $\beta > 0.25$ are presented in the table.
*$P<0.05$; **$P<0.01$; ***$P<0.001$.

The intervention effects established are clinically relevant and consistent. The effects concern several aspects of self-esteem including body image, which is a known predictor of psychosocial functioning [1]. Self-esteem and body image are important issues especially in adolescence. Adolescents with chronic illnesses may become marginalized by peers, rejected for being different at a time when body image and identity so largely depend on conformity [27]. Peer relationships are important for social development and self-esteem especially in adolescents [27]. Therefore, IBD patients should be encouraged and supported in making and maintaining friendships and in participating in peer activities. Our findings indicate that the psychoeducational group intervention is helpful in dealing with physical limitations in relation to activities with peers.

Some limitations of this study should be addressed. Only a small number of adolescents responded to the invitation to participate in the intervention. Unfortunately, low response to interventions is a known phenomenon in adolescents. Consequently, we do not know whether the findings are representative for IBD patients in general. It is advocated that forming homogeneous groups promotes demonstrating effectiveness on the one hand, but over-focusing on the homogeneity of groups may critically reduce the number of eligible participants [8]. Participation of IBD patients in groups with participants with other diagnoses might be similarly effective and easier to implement in clinical practice. Further research on this matter should be considered.

Unfortunately, we lost a considerable number of patients in the experimental group. These dropouts were patients with better behavioral-emotional functioning at baseline than nondropouts. As a result, the intervention effect we found could be overestimated because less improvement could be expected in patients with better functioning before the intervention. Furthermore, we did not monitor

clinical activity of the disease that could have influence on participation as well as on the outcomes.

Another problem in evaluating the effectiveness of a psychoeducational intervention is to identify the contribution of the different components of the intervention to changes in generic measures of adjustment and well being. A limitation of this study is that it does not include the possible influence on the outcome measures of contributive factors such as joining a group of fellow patients and the systematic attention of the group leaders to the participants' well being. This consideration is stressed by the observation of enthusiasm by the majority of participants in evaluating the group experience.

More profound analyses within larger samples are needed to investigate whether specific patients benefit more or less from the intervention. In such a study additional questionnaires should be administered to evaluate intervention-related consequences. In conclusion, we believe that adolescents with IBD benefit from participation in this psychoeducational intervention. Pediatricians and patient associations should encourage adolescents to participate, and stimulate participation in psychoeducational groups as standard psychosocial care.

Acknowledgement

This study has been supported and financed by the Dutch Digestive Diseases Foundation (Maag Lever Darm Stichting, SWO 01-12).

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